DOCUMENT RESUME

ED 477 674 EC 309 647

| | |
|---|---|
| AUTHOR | Ruble, Lisa; Heflinger, Craig Anne; Renfrew, J. William; Robson, Dana |
| TITLE | Medicaid Managed Care and Children with Autism Spectrum Disorders. |
| INSTITUTION | University of South Florida, Tampa. Research and Training Center for Children's Mental Health. |
| SPONS AGENCY | National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.; Vanderbilt Univ., Nashville, TN. Peabody Coll., John F. Kennedy Center.; Substance Abuse and Mental Health Services Administration (DHHS/PHS), Rockville, MD. Center for Substance Abuse Prevention.; Substance Abuse and Mental Health Services Administration (DHHS/PHS), Rockville, MD. Center for Mental Health Services.; Substance Abuse and Mental Health Services Administration (DHHS/PHS), Rockville, MD. Center for Substance Abuse Treatment. |
| PUB DATE | 2002-03-00 |
| NOTE | 6p.; Support provided by the Nicholas Hobbs Society of the John F. Kennedy Center of Vanderbilt University. In: Annual Conference Proceedings--A System of Care for Children's Mental Health: Expanding the Research Base (15th, Tampa, FL, March 3-6, 2002). Chapter 4: Child Welfare and Medicaid. pp281-284. |
| CONTRACT | H133B90022;UR7-TI11304;KDI-TI112328 |
| AVAILABLE FROM | For full text: http://rtckids.fmhi.usf.edu/conference_proceedings.htm. |
| PUB TYPE | Reports - Research (143) -- Speeches/Meeting Papers (150) |
| EDRS PRICE | EDRS Price MF01/PC01 Plus Postage. |
| DESCRIPTORS | *Autism; *Behavior Change; Children; Community Services; Delivery Systems; Elementary Secondary Education; Federal Aid; Financial Support; *Health Services; *Incidence; *Mental Health Programs |
| IDENTIFIERS | Medicaid; Service Utilization; *Tennessee |

ABSTRACT

This study examined the utilization rate of behavioral health services by children with autism spectrum disorders (ASD) over a 6-year period and compared this rate to the expected number of children with ASD in TennCare, Tennessee's managed care Medicaid program. Analysis of TennCare patient data found the rate at which children with ASD received a behavioral health service was 0.24/1000 in Fiscal Year 1995 and 0.57/1000 in Fiscal Year 2000. It notes that, although the rate doubled over time, so did the number of children who participated in TennCare. The paper concludes that the low rate of service use confirms the need for research on service use patterns such as access, type, duration, and continuity of services for children with ASD and the impact of Medicaid-managed care on child and family outcomes. An unexpected finding was the relatively low rate of children reported with ASD receiving services from TennCare. (DB)

Reproductions supplied by EDRS are the best that can be made
from the original document.

ED 477 674

# Medicaid Managed Care and Children with Autism Spectrum Disorders

By
Lisa Ruble
Craig Anne Heflinger
J. William Renfrew
Dana Robson

March 2002

EC 309647

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
This document has been reproduced as received from the person or organization originating it.
Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

BEST COPY AVAILABLE

# Medicaid Managed Care and Children with Autism Spectrum Disorders

**Lisa Ruble**
**Craig Anne Heflinger**
**J. William Renfrew**
**Dana Robson**

## Introduction

In 1994, the state of Tennessee moved to a fully capitated, statewide, managed care Medicaid program called TennCare. TennCare Partners, the behavioral health care arm of TennCare, was developed in 1996. Fully capitated plans like TennCare are expected to result in the greatest cost savings because they have the fewest incentives for cost shifting among payers and the greatest incentives for controlling service utilization (Deal & Shiono, 1998).

Because more states such as Tennessee are experimenting with their Medicaid systems by employing managed care approaches for underserved, low income, and disabled populations, obtaining independent analyses of the impact of these programs on the health care of special needs children is increasingly important. The effect of fully capitated programs like TennCare on service use of children with severe disabilities is unknown, and no data on service patterns of children with complex disorders like autism spectrum disorders (ASDs) are available.

As identified by the *Diagnostic and Statistical Manual of Mental Disorders, IV* (American Psychiatric Association, 2000), ASDs are comprised of five pervasive developmental disorders: (a) Autistic disorder, (b) Asperger disorder, (c) Pervasive developmental disorder, (d) Rett's disorder, and (e) Childhood disintegrative disorder. Table 1 reviews criteria for a diagnosis of ASD. All ASDs are lifelong and result from an underlying neurological insult. No association between ASDs and social economic status, ethnicity, or parenting style exists. Autism, the prototypical ASD, is present before or nearly after birth and affects a child's development in social and communicative behaviors prior to three years of age. An estimated more than 500,000 children between the ages of birth to 18 live in the U.S. A recent epidemiological survey revealed that autism affects approximately 1 out of every 600 children, and ASDs affect about 1 out of every 160 children (Chakrabarti & Fombonne, 2001).

Best practices in autism identify a whole-child approach to treatment as primary (Ruble & Brown, 2002). A whole-child approach requires access to specialists in behavior management, speech and language therapy, and occupational therapy. Other less traditional services such as respite care, in-home personal assistance, counseling, and support are also necessary for many families. Fortunately, these services are within the scope of the guidelines of Medicaid's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) service.

The aim of this study was to determine the utilization rate of behavioral health services by children with ASD over a six-year period and compare this rate to the expected number of children with ASD in the TennCare population.

## Methods

TennCare data available from a previous investigation, the IMPACT Study (Heflinger, Northrup, Saunders, & Renfrew, 2000), were analyzed The IMPACT study was conducted at Vanderbilt University's Institute for Public Policy Studies and was part of a national investigation that examined the impact of managed care on vulnerable populations. Children and adolescents with autism and

*This research was supported by the Nicholas Hobbs Society of the John F. Kennedy Center of Vanderbilt University and the Substance Abuse and Mental Health Services Administration, Centers for Substance Abuse Prevention, Mental Health Services, and Substance Abuse Treatment (UR7 TI11304 and KD1 TI112328). The opinions expressed are those of the authors and do not reflect the opinions of the funding sources.*



BEST COPY AVAILABLE

**Table 1**
**Autism Spectrum Disorders**

| | *Autistic Disorder* | *Asperger Disorder* | *Pervasive Developmental Disorder Not Otherwise Specified* | *Rett's Disorder* | *Childhood Disintegrative Disorder* |
|---|---|---|---|---|---|
| Disordered social interaction | Present | Present | Present | Present | Present[b] |
| Disordered communication | Present | | Present[a] | Present | Present[b] |
| Restricted and repetitive behaviors | Present | Present | Present[a] | | Present[b] |
| Age of onset | Prior to 36 months | | | Prior to 36 months | Between 2 and 10 years |
| Pattern of regression in several areas | | | | Present | Present |
| Average intelligence | | Present | | | |
| Incidence (Chakrabarti & Fombone, 2001) | 16.8/10,000 | 8.4/10,000 | 36.1/10,000 | 1/10,000 | 1/10,000 |

[a] One of these must be present
[b] Two of these must be present

mental retardation serve as an additional population group not targeted in the original IMPACT Study. Existing TennCare enrollment and encounter data for the statewide population of children and adolescents who were Medicaid beneficiaries are available through TennCare files.

After files were extracted and cleaned, data on children with ASD were selected based on ICD-9 codes (U.S. Department of Health and Human Services, 1980) reported in the encounter/claims data. ASDs were identified by ICD-9 diagnostic codes 299.00 to 299.9.

## Results and Discussion

As shown in Figure 1, the rate at which children with an ASD received a behavioral health service was 0.24/1000 in FY1995 and 0.57/1000 in FY2000. Although the rate doubled over time, so did the number of children who participated in TennCare. This low rate of service use confirms the need for research on service use patterns such as access, type, duration, and continuity of services for children with ASD and the impact of Medicaid managed care on child and family outcomes.

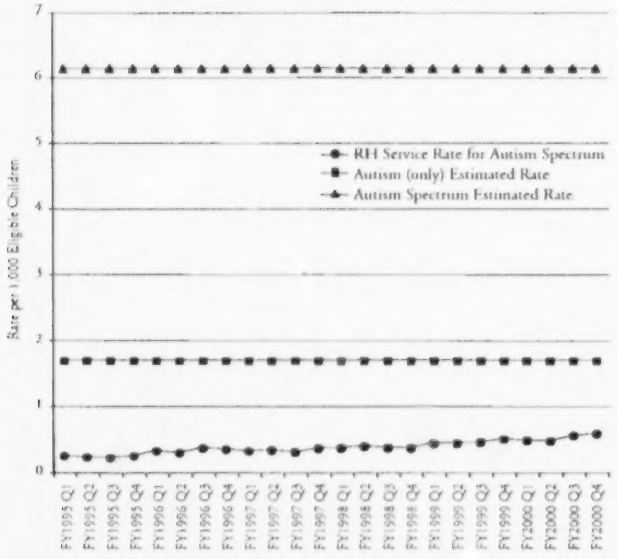
Evaluating the impact of Medicaid managed care programs on the behavioral health care usage patterns of children with complex developmental disorders is critical. The purpose of this study was to describe the rate of service utilization of children with ASDs and compare this rate to the expected number of children with ASD participating in TennCare.

An unexpected finding was the low rate of children reported with ASD. Several possibilities may explain this finding. First, many families may receive services through their local school systems as part of the Individuals with Disabilities Education Act. Second, families may have difficulty locating specialists in ASDs to provide behavioral health services for their child. A third possibility suggests that although ASDs are described in the DSM-IV as a psychiatric disorder, they are also considered to be a developmental disorder. This dichotomy may result in services being disregarded by the managed care organizations and behavioral health organizations due to a lack of medical necessity. Or, service providers may be coding children as having a psychiatric disorder in order to receive reimbursement. Clearly, more information is needed to fully understand why children with ASDs are highly under-represented in this statewide data set.



BEST COPY AVAILABLE

**Figure 1**
**Estimated vs. Actual Service Rate for Children 0-17 Years with Autism**


Rate per 1,000 Eligible Children
RH Service Rate for Autism Spectrum
Autism (only) Estimated Rate
Autism Spectrum Estimated Rate

Although the number of children with ASD doubled over the years, the general TennCare population also doubled, suggesting that the proportional number of children seeking services did not increase over time. This trend contradicts data from the U.S. Department of Education and the California Department of Developmental Services (CDDS). These agencies have published reports documenting autism as the largest growing low incidence disability in terms of numbers of children receiving services (U.S. Department of Education, 1999). The CDDS reported a 273% increase in the number of services provided to children with ASD. More research on the types, patterns, and quality of service use and the impact of managed care on child and family outcomes is necessary.

## References

American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders. (4th ed., Text Revision ed.)*. Washington, DC: American Psychiatric Association.

Chakrabarti, S., & Fombonne, E. (2001). Pervasive developmental disorders in preschool children. *Journal of the American Medical Association, 285*(24), 3093-9.

Deal, L. W., & Shiono, P. H. (1998). Medicaid managed care and children: An overview. *Future Child, 8*(2), 93-104.

Heflinger C. A., , Northrup, D. A., Saunders, R. S., Renfrew, W. (2000 May). *The status of TennCare children and adolescents: Behavioral health, health, service use, and consumer satisfaction: The IMPACT study baseline report on interview data.* Nashville, TN: Center for Mental Health Policy, Vanderbilt Institute for Public Policy Studies.

Ruble, L., & Brown, S. (2002). Pervasive developmental disorders: Autism. In M. Wolraich (Ed.), *Disorders of development and learning* . St. Louis: Mosby.

U.S. Department of Education. (1999). To assure the free appropriate public education of all children with disabilities. *Twenty-first annual report to congress on the implementation of the individuals with disabilities education act (Vol. 2000).*

U.S. Department of Health and Human Services. (1980). *The international classification of diseases: 9th revision, clinical modification: ICD-9-CM.* Washington, DC: Author

**CONTRIBUTING AUTHORS**

**Lisa Ruble, Ph.D.**
*Assistant Professor, Department of Pediatrics, Weisskopf Center for the Evaluation of Children, University of Louisville, 571 S. Floyd Street, Suite 100, Louisville, KY 40202; 502-852-8600, fax: 502-852-7886*

**Craig Anne Heflinger, Ph.D.**
*Associate Professor, Human and Organizational Development, Fellow, Vanderbilt Institute for Public Policy Studies, Vanderbilt University, Box 90, Peabody College, Nashville, TN 37203; 615-322-8275, fax: 615-322-7049; e-mail: c.heflinger@vanderbilt.edu*

**J. William Renfrew, M.A.**
*Research Associate, Human and Organizational Development , Box 90, Peabody College, Vanderbilt University, Nashville, TN 37203; 615-322-6881, fax: 615-343-2661*

**Dana Robson, M.A.**
*Research Assistant, Vanderbilt University, Department of Child Development, 2100 Pierce Avenue, Room 426, MCS, Nashville, TN 38232-3573; 615-322-8141, fax: 615-343-9494*



BEST COPY AVAILABLE

**U.S. Department of Education**
*Office of Educational Research and Improvement (OERI)*
*National Library of Education (NLE)*
*Educational Resources Information Center (ERIC)*

# NOTICE

## Reproduction Basis

| | |
|---|---|
| | This document is covered by a signed "Reproduction Release (Blanket)" form (on file within the ERIC system), encompassing all or classes of documents from its source organization and, therefore, does not require a "Specific Document" Release form. |
| X | This document is Federally-funded, or carries its own permission to reproduce, or is otherwise in the public domain and, therefore, may be reproduced by ERIC without a signed Reproduction Release form (either "Specific Document" or "Blanket"). |